

# Patient-to-patient peer support in renal care: what, why and how?

Patients with kidney disease can often learn and gain support from their fellow patients, and peer support is becoming an increasing area of practice in health care. In the first of a series of articles on the topic, Eleri Wood outlines what it is, why it is recommended and how it can be implemented.

■ peer support ■ kidney disease ■ empowerment ■ self-management

**P**eer support—the help exchanged by patients who share a diagnosis of kidney disease—is gaining attention as a valuable adjunct to traditional renal care. There is increasing awareness that psychological wellbeing impacts on, and is as important as, physical health, coupled with greater emphasis on supporting individuals to self-manage their condition and become expert partners in their care (Department of Health (DH), 2004). Recipients of peer support have been shown to gain the information and confidence they need to take control of life with kidney disease (Hughes et al, 2009) and to find the intervention satisfying. These benefits, in addition to the fact that peer support is extremely low cost and flexible, make it an ideal intervention to help tackle renal medicine's primary challenge: the provision of high-quality, individualised care to increasing numbers of patients despite increasingly confined resources.

As a result it has been promoted as a fundamental component of high-quality renal care (NHS Institute for Innovation and Improvement, 2008). Yet units with formal peer-support programmes remain in the minority, and many of these report problems with take-up and utilisation. This series of articles explores these issues through discussion of the literature and analysis of the experiences of one long-established peer-support programme. It is hoped that this will increase renal professionals' understanding and motivation, and assist in the establishment and development of successful peer-support services, which will be accessible and useful to as many renal patients as possible. This first article explores what peer support actually is, why it is recommended that all renal units have it available to their patients, and important

considerations for those seeking to establish formal peer-support programmes.

## What is peer support?

*'Peer support, within the health-care context, is the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person' (Dennis, 2003:329).*

Peer support is a complex and highly variable intervention. A popular definition, proposed by Dennis (2003), tells us that it occurs when patients are put in touch with each other for the specific purpose of giving and receiving assistance with issues related to their common diagnosis. However, most renal patients already receive assistance from a variety of sources, most notably health-care professionals and their own friends and families. What this definition does not tell us is how or why patients may gain additional benefit from assistance from a peer.

Primarily, the distinct benefits of peer support derive from the fact that only another renal patient can share the personal experience of living with kidney disease. As a result, peers have a unique authenticity, which enables recipients to compare, validate and normalise their own experience—what Dennis refers to as 'appraisal assistance' (Dennis, 2003). It also means they have a wealth of real-world knowledge about life with kidney disease, enabling them to provide informational assistance. Not only will the content of this information be different to that provided by professionals, in that it will largely relate to practical and lifestyle issues, it will also be delivered in easy-to-understand layman's terms. Lastly, what Dennis terms emotional assistance is the empathy, reassurance and encouragement that peers

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easily share as a result of their common predicament (Dennis, 2003). A number of psychological concepts provide the theoretical explanation for these effects. Peer support is a social intervention and thus underpinned by the biopsychosocial model, which assumes there are multiple multidirectional relationships between biological, psychological and social processes (Engel, 1977). Any source of social support can facilitate positive adjustment and buffer the effect of stressors associated with living with chronic kidney disease (CKD) (House et al, 1988) but the unique processes which occur through contact with peers require further explanation. The process of appraisal against peers is conceptualised in social comparison theory: when people are confused about their internal sensations, for example, when feeling anxious about a diagnosis of CKD, peers can help them interpret the appropriateness of what they are feeling. Both upward (with peers healthier than themselves) and downward (with peers in poorer health) comparisons can improve wellbeing, although comparisons and outcomes can be negative as well as positive (Festinger, 1954). Social learning theory (Bandura, 1997) provides a framework for how behaviour can be influenced through self-efficacy, i.e. an individual's belief that they are able to perform an activity. Peer support can enhance self-efficacy through vicarious experience (the provision of a credible role model who has mastered the skill of living with CKD) and social persuasion (verbal encouragement and expression of belief in the individual's abilities).

Further benefits result from the distinct nature of relationships between peers compared to other means through which patients gain support. For example, patient-clinician relationships are usually hierarchical and directed by the clinician, whereas peers are, by their very nature, equals. As one recipient of peer support commented: 'there was no white coat between us' (Hughes et al, 2008:31). Friends and family can increase a patient's isolation and distress by offering unhelpful (albeit well-intentioned) assistance, such as unwanted advice or false reassurance, while a peer is more likely to allow and accept the open expression of feelings of a fellow sufferer of kidney disease. Additionally, some individuals do not wish to burden loved ones so avoid seeking their support (Taylor and Gutteridge, 2013). This does not mean, however, that peer support is suggested to replace patients' regular sources of assistance, rather that it is recognised as a complementary addition to standard renal care.

Part of peer support's usefulness stems from the control users can have over when, how and for what purpose they call on it; although this does rely on their local peer support programme having such

flexibility. Some patients benefit from receiving peer support early in their renal career, for example to help them understand and accept a specific diagnosis such as lupus. Others will only desire the support of a peer later, perhaps when facing renal replacement therapy decisions or to help adjustment to a change in lifestyle after starting dialysis. Many find it useful to meet their supporter face-to-face but some prefer the convenience of phone or email interaction, and while some benefit from a single contact others value the opportunity to build longer-term relationships (often called 'buddying'). The fact that recipients have direct influence over the purpose for and manner in which they receive peer support makes it an extremely responsive and individualised intervention.

## Evidence of the benefits

Peer support has been proposed to benefit patients in a range of physical, emotional and behavioural ways, but in order to utilise it appropriately professionals need a realistic and evidence-based understanding of its effects on recipients. Unfortunately, there are few studies of peer support in renal care so it is useful to include analysis of other long-term conditions, such as diabetes, HIV, heart failure and cancer. Evidence of the effects of peer support across all these conditions has been summarised in a literature review published by NHS Kidney Care in 2011, which found that impacts on measurable physical outcomes, such as mortality, depression or biochemical markers (HbA1c, cholesterol), are small and unreliable. However, there is consistent evidence of a number of 'softer' benefits, particularly increased feelings of reassurance, acceptance, improved confidence and ability to cope, and participants' satisfaction with the intervention. The review concludes that peer support can be a valuable and satisfying method by which patients access emotional and social assistance, but also notes that the value of the conclusions which can be drawn from the literature is limited by widespread poor methodology in terms of inadequate design, description and evaluation quality (NHS Kidney Care, 2011).

*Table 1* summarises the better quality studies focused on formal peer support in renal populations: quantitative trials with no comparison group and qualitative studies without a recognised evaluative framework have been excluded. They demonstrate a range of psychological benefits, including reassurance and empowerment (Perry et al, 2005; Hughes et al, 2009; Taylor and Gutteridge, 2013), acceptance and a reduced sense of isolation (Hughes et al, 2009; Sattoe et al, 2013; Taylor and Gutteridge, 2013), and increased hope, encouragement and positive role modelling (Perry et al, 2005; Hughes et al, 2009; Sattoe et al, 2013). There is also some

**Table 1. Studies providing evidence of outcomes of peer support in renal populations****Perry et al, 2005**

A randomised controlled trial (RCT) that evaluated the impact of peer support on completion of advance directives in a US population of 203 haemodialysis patients. Peer-support recipients were four times as likely to complete an advanced directive compared with control groups and significantly more comfortable during advanced directive discussions. The influence was more significant among African American participants.

**Hughes et al, 2009**

A qualitative analysis of the experiences of 20 UK recipients of peer support, the majority of whom received peer support while they were CKD Stage 4 and were positive about their experience. Several key benefits were identified: being able to talk to someone 'who's gone through what you're going through'; being reassured, encouraged, and gaining confidence, leading to greater sense of control; access to first-hand practical information; and help in adjusting to life with kidney disease, coming to terms with starting treatment, and making or confirming treatment decisions.

**Harden et al, 2012**

A before and after study that compared the clinical outcomes of two groups of patients transferring from paediatric to adult services. Those who transferred through a new integrated service that facilitated peer support were deemed to be more adherent to medication and engaged with health-care providers (as judged by reduced transplant failure rates) than a historical set of patients transferred directly to the adult service. However, the specific effects of peer support could not be separated from the effects of the overall intervention and the sample size was small at only 21 total participants.

**Chen et al, 2011**

An RCT that examined the impact of a self-management support programme (which included peer support) on 54 Taiwanese CKD Stage 4 patients. Patients were followed up over 12 months, at which point recipients of the support programme showed significantly lower rates of renal progression and hospitalisation compared with the control group. However, it was not possible to separate the effects of peer support from the rest of the intervention.

**Sattoe et al, 2013**

A mixed-methods evaluation of the impact of a Dutch camp led by adult renal patients ('buddies') on the young attendees who were still to transfer to adult services. Semi-structured interviews were conducted with 19 participants and combined with surveys among 62 participants. Participants reported a number of positive effects of having a buddy, including increased self-confidence and improved self-management abilities.

**Taylor and Gutteridge, 2013**

A qualitative exploration of the perceptions, attitudes and motivations in relation to peer support among 26 patients and carers. Peer support was seen to have specific attributes and benefits beyond those of support provided by family and friends; despite this a number of emotional and practical barriers prevented wide uptake of formal peer-support opportunities. Carers identified as much of a need for peer support as patients. Ideal peer support relationships were felt to involve establishment of a good sense of rapport and reciprocal sharing.

evidence that peer support can affect beneficial behaviour change such as improved self-care (Chen et al, 2011; Harden et al, 2012; Sattoe et al, 2013) and increased participation in advance planning (Perry et al, 2005). Furthermore, the findings demonstrate peer support's potential to particularly benefit patient groups which renal professionals often struggle to engage with, such as ethnic minorities and young adults (Perry et al, 2005; Harden et al, 2012; Sattoe et al, 2013).

It is important to acknowledge that peer support can also lead to negative outcomes. For example, a minority (10%) of the recipients interviewed by Hughes et al (2009) described being frightened by the information provided by their peer supporter. The authors advise that the risk of adversely affecting patients in this way should be minimised by ensuring supporters are appropriately skilled to demonstrate sensitivity to the needs of each recipient, and that recipients enter peer support willingly rather than being pressurised or co-opted into the intervention. Variable levels of uptake indicate that it is not universally attractive but satisfaction levels among willing participants are consistently high (NHS Kidney Care, 2011). Adequate training of supporters is important to minimise other potential hazards. The risk of recipients receiving inaccurate clinical information can be reduced by ensuring that supporters' knowledge is reviewed and refreshed, and that they are explicitly instructed not to give medical advice. Additionally, well-prepared supporters are likely to feel more confident and able to cope with the emotional challenges of the role (Seymour et al, 2013) and can find providing support as valuable and beneficial as receiving it (Brunier et al, 2002; Sattoe et al, 2013).

**A pragmatic approach?**

Informal peer support can be seen every day in every dialysis unit, kidney ward or waiting area where patients meet and talk. It also happens on the internet (through forums such as [ihatedialysis.com](http://ihatedialysis.com)) and many renal clinicians introduce patients to each other in order to enable one to learn or obtain support from the other. The evidence suggests that information received from peers through these informal channels has significant influence. For example, patients have reported that it can facilitate adherence to haemodialysis regimes (Griva et al, 2013) and two systematic reviews have examined how people with chronic kidney disease make decisions about renal replacement therapy options and concluded that the influence of peers can be powerful and persuasive, possibly more so than the influence of clinicians (Morton et al, 2010; Harwood and Clark, 2013). As a result of this finding, Morton et al recommend the formal incorporation of peers into CKD patient education, but not everyone agrees. Winterbottom et al (2012) argue that patients making decisions on the basis of another patient's opinions and experiences will use heuristic processing rather than systematically evaluating all the pros and cons, and thus be at greater risk of making a 'bad' decision (although they do acknowledge the benefits of experienced patients in terms of helping other patients to cope

with and adjust to their illness). However, for many, the fact that patients will be influenced by their peers whether professionals encourage it or not leads to the pragmatic conclusion that clinicians might as well gain some control over the accuracy of the information provided and the skills of the supporters by embracing the phenomenon and establishing formal peer-support programmes. Moreover, patients express a strong preference for receiving support from trained peers (Ieropoli et al, 2011) and satisfaction increases with the supporter's ability to demonstrate sensitive listening skills, empathy and understanding (Hughes et al, 2009).

There is a further pragmatic argument for adoption of formal peer support by the renal community. The NHS is facing shrinking financial and human resources while renal disease is increasing in prevalence. Experienced renal patients represent a huge, enthusiastic and free resource that could help address these challenges. However, it should be noted that establishing and maintaining a peer-support service, while requiring only a modest financial outlay, will require a significant commitment and the time of a core group of staff and should only be promoted as a useful supplement to, not a replacement for, existing clinical services (NHS Kidney Care, 2013).

## National position on peer support

Over recent years a raft of policies, mandates and publications have sought to improve the outcomes and experiences of patients with long-term conditions through particular emphasis on the importance of encouraging patients to take greater responsibility for their health (DH, 2006; 2011; National Institute for Health and Care Excellence (NICE), 2012). A similar focus can be seen in the first of the *Renal National Service Framework* standards which advocates the development of a patient-centred service in which patients are informed partners in their care (DH, 2004). Peer support, having been shown to be a useful strategy for empowering patients, can play a valuable role in achieving these improvements. Perhaps because pre-dialysis care is recognised as a period during which patients can particularly gain from peer support, publications which explicitly recommend the inclusion of peer support in renal care target this area. The NHS Institute for Innovation and Improvement (2008) states that peer support is a 'fundamental service component' of high quality pre-dialysis care and the Renal Association recommends 'access to expert patients' in its pre-dialysis guideline (Farrington and Warwick, 2009). In 2011, NHS Kidney Care commissioned a programme of work to raise awareness among clinicians for peer

support benefits and provide assistance to those seeking to embed formal services in their renal units (NHS Kidney Care, 2011).

Despite these recommendations, a survey of the availability of peer support in English renal units in 2012 revealed that only 30% had, or were in the process of establishing, formal peer support services (NHS Kidney Care, 2013). Units without peer support reported high levels of interest but a number of operational barriers which prevented creation of programmes, including lack of staff time and uncertainty regarding how to go about it. Therefore the rest of this article provides a brief summary of the actions and considerations necessary in order to set up a patient-to-patient peer-support service.

## How to establish a peer support service

The following people will need to be involved from the beginning:

- A team of highly motivated clinical champions with dedicated time to co-ordinate the project. They will have responsibility for recruitment, training and other organisational aspects. Ideally they should comprise a varied multidisciplinary group so that they have influence and the ability to promote peer support across the whole unit.
- Patients and carers, either through the local patient association or by appealing directly for interested individuals with posters in patient areas. Their input is vital for creation of a locally relevant and successful service.
- Senior management, without whose support it will be difficult to embed and sustain the service.
- The Trust's volunteer team who will help with the processes required before volunteers can undertake formal peer support. These commonly include disclosure and barring service (DBS) checks and local induction but exact requirements vary between hospitals; check early to prevent project delays.

The objectives of the service and form of support to be offered will need to be agreed:

- Will the service cater to just patients or include carers, prospective donors, etc?
- Will contact be offered individually or in groups; as a one-off intervention or long-term buddying; face-to-face, by phone or email; or all of these?

Consider starting small and focused with one particular style and target group to build confidence and momentum before broadening to include different formats and the whole renal unit population. Arrangements will then need to be made for:

## Key points

- Peer support can be a useful and valued adjunct to the support and assistance renal patients receive from professionals and their friends and family
- There are few studies of peer support in renal populations, but kidney patients have been shown to benefit in a variety of ways including greater knowledge and confidence, a sense of reassurance and acceptance, and increased empowerment
- Although promoted as a fundamental component of high-quality renal care, units with formal peer-support programmes remain in the minority
- Establishing a peer-support service requires time and effort from a core group of peer-support champions but little financial outlay. Resources and assistance are available

- Recruitment of patient volunteers. This can be done through direct advertisement using posters and leaflets. However, it is useful for clinicians to also identify and approach individual patients in order to ensure an appropriately experienced and demographically mixed pool of supporters.
- Training the volunteers, which is crucial for a safe, high-quality service. As a minimum, this should cover expectations and boundaries of the role, basic communication skills, how to deal with potential problems, and the practicalities of the service. Two group sessions of 2–3 hours each usually suffice (contact the author for resources).
- Practical procedures for running the service, which includes:
  - Mechanisms of referral: a peer-support email account can be useful as this is not attached to one individual, but a small number of clinicians who will filter and act on referrals should be identified
  - Documentation of referrals and sessions: a single electronic spreadsheet or database accessible via the unit's server is ideal
  - Where support sessions will occur and how they will be arranged: although time-consuming, it is recommended that clinicians negotiate a mutually agreeable time, format and location for each support session and confirm this with both parties in writing to minimise misunderstandings and non-attendance.
- Supporting the supporters. Supporters should have an easy means of contact with a peer support clinician in case of problems. Other support mechanisms, such as regular group meetings, can be agreed according to local preference.
- Initial and ongoing promotion and advertisement of the service to staff and patients. This is essential for effective utilisation of the service and will be discussed further in subsequent articles in this series.

- Service evaluation, which is necessary to ascertain how well the service is meeting its aims and inform ongoing development.

## Conclusions

There is good evidence to suggest that peer support is widely liked and valued by renal patients. Recipients most commonly report benefits such as greater knowledge and confidence, reassurance from meeting a positive role model and a reduced sense of isolation. It has been shown to help disease adjustment, assist treatment decision making, and increase empowerment and self-management behaviours, and is recommended as an important component of high-quality renal care. However, currently only a minority of patients in the UK have access to formal support programmes. It is hoped that this article has increased understanding of the need to ensure peer support is available for every renal patient, and stimulated the motivation and confidence to help make it a reality. **JRN**

## References

- Bandura A (1997) *Self-efficacy: the exercise of control*. Worth Publishers, New York
- Brunier G, Graydon J, Rothman B et al (2002) The psychological well-being of renal peer support volunteers. *J Adv Nurs* **38**(1): 40–9
- Chen SH, Tsai YF, Sun CY et al (2011) The impact of self-management support on the progression of chronic kidney disease – a prospective randomised controlled trial. *Nephrol Dial Transplant* **26**(11): 3560–6
- Dennis CL (2003) Peer support within a health care context: a concept analysis. *Int J Nursing Studies* **40**(3): 321–32
- Department of Health (2004) *National Service Framework for Renal Services: Dialysis and Transplantation*. Her Majesty's Stationery Office, London
- Department of Health (2006) *Supporting people with long term conditions to self care: a guide to developing local strategies and best practice*. Her Majesty's Stationery Office, London.
- Department of Health (2011) *NHS Outcomes Framework 2012/13*. Her Majesty's Stationery Office, London
- Engel GL (1977) The need for a new medical model: a challenge for biomedicine. *Science* **196**(4286): 129–36
- Farrington K, Warwick G (2009) Planning, Initiating and Withdrawal of Renal Replacement Therapy. The Renal Association Clinical Practice Guideline. <http://tinyurl.com/llt5yar> (accessed 23 June 2014)
- Festinger L (1954) A theory of social comparison processes. *Human Relations* **7**(2): 117–40
- Griva K, Ng HJ, Loei J et al (2013) Managing treatment for end-stage renal disease – A qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence. *Psychol Health* **28**(1): 13–29. doi: 10.1080/08870446.2012.703670
- Harden P, Walsh G, Bandler N et al (2012) Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. *BMJ* **344**: e3718 doi: 10.1136/bmj.e3718
- Harwood L, Clark A (2013) Understanding pre-dialysis modality decision-making: a meta-synthesis of qualitative studies. *Int J Nurs Stud* **50**: 109–20. doi: 10.1016/j.ijnurstu.2012.04.003
- House J, Landis K, Umberson D (1988) Social relationships and health. *Science* **241**(4865): 540–5
- Hughes J, Wood E, Cox S et al (2008) No White Coat Between Us:

- Developing peer support services for kidney patients. Modernization Initiative, London
- Hughes J, Wood E, Smith G (2009) Exploring kidney patients' experiences of receiving individual peer support. *Health Expect* **12**(4): 396–406
- Ieropoli S, White V, Jeffors M, Akkerman D (2011) What models of peer support do people with colorectal cancer prefer? *European J Cancer Care* **20**(4): 455–65. doi: 10.1111/j.1365-2354.2010.01218.x.
- Morton F, Tong A, Howard K et al (2010) The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ* **340**: c112. doi: 10.1136/bmj.c112
- NHS Institute for Innovation and Improvement (2008) *Focus on: Preparing for End Stage Renal Disease*. NHS Institute for Innovation and Improvement, Coventry
- NHS Kidney Care (2011) *Peer Support: Options and Effectiveness*. NHS Kidney Care, London
- NHS Kidney Care (2013) *You're not alone: peer support for people with long term conditions*. NHS Kidney Care, London
- National Institute for Health and Care Excellence (2012) *NICE Quality Standards*. NICE. [www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp](http://www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp) (accessed 23 June 2014)
- Perry E, Swartz J, Brown S et al (2005) Peer Mentoring: A Culturally Sensitive Approach to End-of-Life Planning for Long-Term Dialysis Patients. *Am J Kidney Dis* **46**(1): 111–9
- Sattoe N, Jedeloo S, van Staa A (2013) Effective peer-to-peer support for young people with end-stage renal disease: a mixed methods evaluation of Camp COOL. *BMC Nephrol* **14**(1): 279. doi: 10.1186/1471-2369-14-279
- Seymour JE, Almack K, Kennedy S, Froggatt K (2013) Peer education for advance care planning: volunteers' perspectives on training and community engagement activities. *Health Expect* **16**(1): 43–55. doi: 10.1111/j.1369-7625.2011.00688.x
- Taylor F, Gutteridge R (2013) Overcoming barriers and facilitating access to peer support for CKD patients and carers. West Midlands Central Health Innovation and Education Cluster: <http://tinyurl.com/p6sdwaw> (accessed 23 June 2014)
- Winterbottom AE, Bekker HL, Conner M, Mooney AF (2012) Patient stories about their dialysis experience biases others' choices regardless of doctor's advice: an experimental study. *Nephrol Dial Transplant* **27**(1): 325–31. doi: 10.1093/ndt/gfr266